

## **Re-designing dementia**

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# Re-designing dementia

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# Time travel

Taking you back to  
2006...



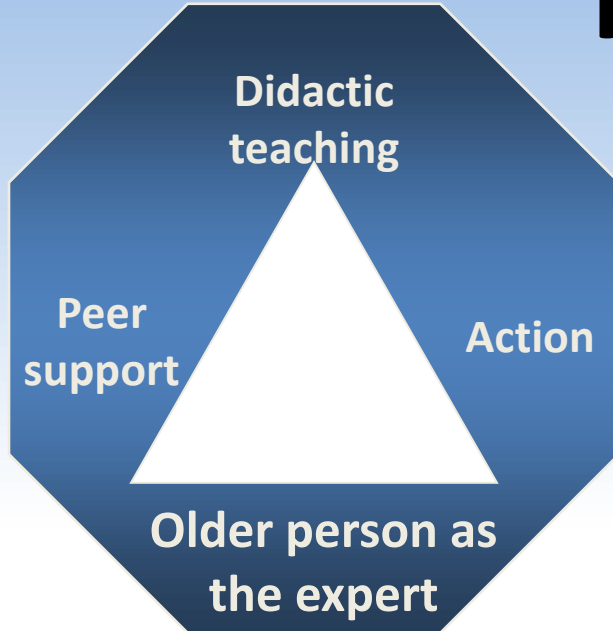
# In the dementia world...

I was still reeling from the shock of just having being diagnosed with Alzheimer's Disease. I picked up the phone and tentatively managed to ring the number for the Alzheimer's Association...the response was that there was very little available that would be suitable as most was directed towards the carer.....

Christine Bryden



# In my world...



Being told I had dementia was like a door re opening after a difficult time in my life – new challenges, new opportunities.

I want people to understand that dementia isn't an end, it's a new beginning where you do things differently. While some things change forever there is a lot you still can do.

***James Mckillop***



- Could the principles of Lifestyle Matters be translated into a programme to support people with living dementia post-diagnosis?





# What people with dementia told us were the elements that made up a good post-diagnostic support programme (2006)





# Do people with dementia want a programme of this nature?

- Yes!
- We don't just want to sit and talk we want action!
- We have other things to cope with – not just dementia  
*'it is hard enough getting dressed never mind putting one of these [pointing to splint on hand] on here.'*

*Give the person with dementia some hope to cling onto. Show them that dementia makes you change your life but you can still be happy and productive.*



# The content of the programme

- How to do the things I enjoy. I don't want to sit around talking about dementia all the time. It's depressing!
- Ways to maintain meaningful roles such as volunteering, it's the one time that people treat you like a person, it gives you distance you know.



# Opportunity to discuss issues that are **‘taboo’: sex and chocolate**

I have to ask my wife to hide all chocolate, otherwise I would sit and eat it all day. I’ve heard a number of people with dementia talk about this craving but I’ve not read about it anywhere.

I’d never been interested in chocolate before so it did feel a bit strange at first and it is the kind of thing that is easily misinterpreted by others.



# See the whole person and recognize the complexity of people's lives

- We have other things to cope with – not just dementia, 'it's hard enough getting dressed, never mind putting one of these [pointing to splint on hand] on here'



# Importance of customisation of the intervention

‘Once you’ve met one person with dementia,  
you’ve met one person with dementia’



# Facilitation of sessions: the atmosphere

- Sessions should be enjoyable. Living with dementia is difficult at times and the last thing you want is to go to a meeting that is dull and depressing.
- We don't just want to talk about dementia. We spend enough time thinking about it, we want to have some fun.



# How information is provided

- There isn't a need to rush. We need time to digest information. Keep the pace steady so that the information is easy to follow





# Aids to support memory

- It can be helpful to make written notes on a flip chart as the meeting progresses. This can act as a visual prompt so that people with poor short-term memory can follow the information.
- Facilitators can then type this information up and give it to group members as a reminder of the content of sessions. Short DVDs could be made available of the factual information provided within the programme



# The structure of sessions

I found out the hard way that people with dementia do not have a great attention span. I run my meetings with an informal session: tea, coffee and biscuits half an hour before the starting time

I do not plan to go on longer than an hour...people can stretch their legs and go outside for a smoke. If you go on too long you lose the smokers!



# Where groups are held: the environment

Noise can be very distracting and it can be difficult to follow lots of conversations when they are all happening at once. It's helpful to talk in small groups and if everyone is speaking to the whole meeting, people should take it in turns so that others can listen.



# Involvement of carers?

Yes....but...

I think, and it is a personal thought, not an official one, is that carers and people with dementia should have their own distinct groups

My initial thoughts are that some things might be done better together to save time having a specialist speaker having to come twice...both parties will be in their own state of shock and hopefully both being together at the one event will remember what has been said.



People with dementia will want to get to know others and talk on their own terms. They will have to try and rebuild their self confidence and not be looking over their shoulder at their carer. They may talk confidentially among their peers and share worries but not repeat them with the carer present in a group in case they upset and distress their loved one.

So you see the dilemma. Free speech, honest dialogue and thoughts can be constrained through no fault of anyone. Each wanting to protect the other. Do you without dementia speak differently when your partner is in the room? Yes!! Well we are no different.



# Refining of the ideas: finding ways to structure and scaffold conversation to build understanding

Meeting new people



Asking questions



Discussions



Sharing worries





Engaging with groups (10 studies over 10 years)





# Developed through this process...

- A manual
- A resource for people with dementia
- A training programme for facilitators
- Each developed in partnership with people with dementia



# Presented a menu of themes

## **Understanding dementia**

Welcome and introduction

Ways of thinking about dementia

Dementia as change

## **Living with dementia**

Health, wellbeing and activity

Making the most of routines

Enabling environments

Enhancing communication

Memory maintenance

## **Relationships**

Building and maintaining friendships

Managing conflict

## **Keeping physically well**

Keeping physically well

Keeping physically active

Diet and dementia



# Presented a menu of themes

## **Keeping mentally well**

Experiencing emotional wellbeing  
Sleep

## **Dementia and daily living**

Dining as an activity  
Safety in the home and community  
Managing finances

## **Building and developing skills**

Hobbies and leisure  
Learning something new  
Mastering computers and mobile telephones  
Taking time out: holidays and short breaks

## **Keeping connected**

Maintaining community connectedness  
Transport

## **Planning for the future**

Tapping into future support  
Moving forward: celebration and endings



# Each session has a familiar structure

- Welcome and sharing of aims
- Information giving (to set the context)
- Group discussion topics (building shared understanding, drawing on strengths, validation)
- Practical activity: opportunity for active experimentation



# What people with dementia told us they valued about the intervention

What you've done for us has got me to the top...its put me back where I used to be..what we've been doing in here and saying and thinking has done me so good. I feel like a new person...I'm not showing off...you got me there honestly...if you'd seen me not too far back...off my food...coming here is the thing that got me back to the top.



# Enabling approach adopted

- I've got confidence
- Yes, it's confidence what held me back...that's what you've given me



# Creation of a supportive atmosphere

I think it's being like minded here. It's really comforting to know that you could say anything you wanted and that you aren't going to be sniggered at....

You've got time for us....we can ask questions...when you're at home and you say something you can see people raise their eyebrows...you're not like that...people think were daft but I'm not daft....coming here I took a load of those books last week....and I stopped up and read them...it gives you confidence because you think you can alter. It has given me confidence

People don't want to know about us and you do. You can really feel that.





# Content

Rather than just talking I've been able to learn things about memory

I think this group teaches people about memory techniques and then they can use these when they visit other social groups.

You know you're telling you things that could alter your life



Meeting new people - In similar experiences..

Having a laugh about some things alongside learning.

A release.



# To the present...



# Not so new but more in line with our policy

- Within the United Kingdom:
- Policy has very much focused on importance of delivering a timely diagnosis
- G8 Summit on Dementia (2013) prioritized early intervention and care in community and people's own homes



- Increasing recognition that it is not enough just to give a person with dementia a diagnosis
- Value of evidence based psychosocial interventions for people with dementia and their carers is recognized
- UK has pledged to provide community based programmes which aim to improve quality of life for people with dementia and their carers



- Shift is very gradually occurring in relation to understanding the needs of people with dementia and of finding ways to listen to their experiences



# However...

- Mountain et al (2016) have highlighted the lack of robust evidence and a high level of uncertainty regarding what should be offered to meet the needs of people post-diagnosis





*A growing societal movement to promote living well with dementia, along with policy promoting an early (timely) diagnosis has increased the realization that people with early stage dementia can be enabled to self-manage, challenging long-standing perceptions.*



# Where we are at present: from a local to a global population

- Randomised controlled trial of 42 months duration funded by NIHR HTA (2,000,000.00)
- 10 study sites including Sheffield, Nottingham, Hull and others (still seeking interested sites)
- Intervention delivery to commence early 2017
- Recruitment target 486



# What will people in the RCT be offered?

- 12 week programme for people recently diagnosed with dementia
- Participants meet weekly in a facilitated group of 10-12 in a community venue
- They also have a monthly 1:1 with one of the facilitators the first being before the group commences



- Supporters can be invited but their involvement is limited to weeks 1,6 and 12 of the group and in 1:1 sessions if the person with dementia considers it to be helpful
- An essential aspect of the programme is enactment of activities in the community, not just talking about it



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